

DEAD TOO SOON?

SPINAL CORD INJURY AND QUALITY OF LIFE

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EXECUTIVE SUMMARY

Those who have never experienced a spinal cord injury and see people living as quadriplegics have a difficult time associating this condition with a high quality of life.

Yet scientific research shows individuals with a spinal cord injury (SCI) do recover joy in their lives.

Research shows that the following aspects play a large role in the recovery of quality of life in those with an SCI:

- **Social involvement** is vital to a high sense of life satisfaction ¹
- **Family:** People with SCI were significantly happier with their family life than the general population²
- **Dignity-affirming relationships:** Dr. Harvey Chochinov writes, “[t]he reflection that patients see of themselves in the eye of the care provider must ultimately affirm their sense of dignity”³
- **Adjusting to change over the passage of time:** With the help of supportive family and community, individuals with an SCI can sustain a high quality of life, even in the face of complications brought on by age

Recommendations

- Given that research shows the passage of time is one of the requirements of returning to a joyful life after a tragic accident, the option of legalized assisted suicide cuts off the very process that would allow a patient to recover meaning. Assisted suicide for people with a spinal cord injury should never be made legal
- Increased education to help children and adults to accept and understand that persons with an SCI can and do regain a high quality of life post-injury
- Government should continue to support local and provincial rehabilitation centres
- Families and spouses who are able to journey together through the changes brought on by a spinal cord injury can be foundational to the quality of life of their loved ones just by virtue of the dignity and respect given during that journey

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FROM THE OUTSIDE LOOKING IN

When Christopher Reeve fell from his horse, his life changed beyond imagination. It was a fall from being Superman, at least on screen, to living with the help of ventilator as a quadriplegic. Yet Mr. Reeve garnered much praise for the way he continued to live after the accident, an example of how even a tragic accident can result in a meaningful life.

In public perception at least, there is a difference between Superman and a man in a wheelchair breathing through a respirator. What kind of quality of life can a person with a spinal cord injury (SCI) resulting in paraplegia or quadriplegia have? As much as we might strongly value the contributions of individuals living with a spinal cord injury, most active people believe that life after a paralyzing accident would be unbearable. The authors of a 2003 study concur, writing that “[t]he widespread view of a good quality of life is usually based on the idea of good health and experiencing personal well being and life satisfaction e.g. independence, fitness, status and respect.”⁴

By this definition, it seems impossible that someone with a spinal cord injury could have, or even hope to have, a high quality of life. A case in point is one study of emergency room physicians which found that “(o)nly 18 per cent imagined they would be glad to be alive with a severe SCI (spinal cord injury), compared with 92 per cent of a true SCI comparison group.”⁵ In short, the question of quality of life for a person with a spinal cord injury is one that only those with an SCI can accurately assess. Studies show those without such an injury have a very different understanding of life and its quality.

How and why do people with a severe spinal cord injury maintain a high quality of life? A 2005 review of quality of life studies related to SCI helps to understand:

*Individuals with SCI may object to the fact that the “societal,” outsider view reflected in the scoring of utility (usefulness as a measure of quality of life) measures does not correspond at all with their own insider views. To these individuals, paralysis and the mobility and physical activity limitations that result are at best major irritations that, with adequate societal and personal arrangements in place, need not detract from wellbeing and a satisfactory life—on a par with that of the average nondisabled person.*⁶

Research shows individuals with a spinal cord injury can regain and maintain a high quality of life for years after their injury. Indeed studies of the lives of spinal cord injury patients show they can live well in the context of a “new normal”.

The following are major contributors to a high quality of life for such individuals:

Social Functions

Among individuals with a spinal cord injury, those who are able to interact well socially with their partners or spouses, their family and their friends report a higher level of life satisfaction than those who can't.⁷

Particularly for those considered “different” rather than “normal”, social involvement is a two way street, requiring spouses, friends, family and even society at large to make it possible. If public spaces are made inhospitable by stairs and non-ramped curbs, no amount of invitations to go to a concert will help. If private homes make it impossible to enter, or navigate inside the home, a person in a wheelchair is unlikely to visit often.

Dignity-affirming social interactions

The self-perception of persons with a spinal cord injury is not built solely on how they feel other people see them. However, personal interactions can be a source of encouragement or discouragement, joy or frustration, dignity or humiliation depending on how the other person perceives the person in the wheelchair. Speaking on the basis of years of research into the nature of dignity in terminally ill cancer patients, Dr. Harvey Chochinov writes: “The reflection that patients see of themselves in the eye of the care provider must ultimately affirm their sense of dignity. At least in part, it would appear, dignity resides in the eye of the beholder.”⁸

While dignity is a complex concept, affirming dignity can start with changes such as seeing past the wheelchair to the person in it. The conclusion that “dignity resides in the eye of the beholder” bears truth for everyone who cares for, lives, works or recreates with a person with a spinal cord injury.

“Significant correlations also exist with two items on social and partner relationships (change in relationships and degree of satisfaction in love life): the mean QoL [quality of life] score of those who report of partial or total changes in relationships is lower than that of those who claimed no changes...”¹⁰

Family

Another study comparing the quality of life of people with a spinal cord injury to that of the general population found that persons with an SCI actually had higher life satisfaction than the general population “[o]n all three social items (partnership relations, family life, and contacts, friends and acquaintances)... but this ... was only (significantly higher) on the family-life item.”⁹

Contrary to the opinions of the general public, note here that people with a spinal cord injury scored *higher* in terms of their quality of life than did people without such an injury on three social items. They rated their quality of life with respect to their family significantly higher than did people without any spinal injury.

Similar to the rest of the population, stable, secure relationships are a source of satisfaction with life. But the reverse is also true, insofar that being unable to function well socially and in family circles is a detractor from quality of life. Dijkers (2005) found that “what affects wellbeing is the impact of these impairments on the capacity for self-care and mobility and especially on the ability to fulfill ‘normal’ social roles and to participate in family and social life.”¹¹

Therefore, the ability or inability to be an active part of a family circle is, once again, not the sole responsibility of the individual with a spinal cord injury.

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LEARNING TO LIVE WITH SPINAL CORD INJURY

Numerous longitudinal studies have been conducted on the perceived quality of life of persons with spinal cord injuries. Researchers McColl *et al.* found “that fatigue and negative perceptions of aging were more prevalent among the younger participants with shorter durations of disability than among the older subjects.”¹² That is, the longer a person lives with a spinal cord injury, the less fatigue and fear of aging they will have. Personal wellbeing is also not destroyed by a spinal cord injury. According to a 25-year study following the lives of individuals with such an injury, “despite (the fact that study participants had) lived an average of more than 32 years with SCI, declines in wellbeing are not universal to all areas of life.”¹³ While the passage of time does require constant adjustment to the increasing or decreasing limitations of injury, SCI does not automatically equate with an unrecoverable level of self-perceived quality of life.

Research shows, then, that what makes for a high quality of life for people with a spinal cord injury is in fact very similar to what makes for a high quality of life for most people: family, social function, dealing with the passage of time. However, the standards by which those with SCI judge their quality of life are more nuanced and/or complicated than the aforementioned standards set by society at large.

WHEN THE DESIRE FOR DEATH IS PERSISTENT

Some individuals with spinal cord injury do not desire to live this new, substantially altered life. Despite the encouragement and companionship of rehabilitation staff, their families and friends, a minority of persons with this type of injury may still persistently request to die.

“Clinicians who work with persons with SCIs acknowledge that virtually all newly injured persons have thoughts of wishing to die, but there are very few who persist in or act on those thoughts.”¹⁴

Where does the law currently stand with respect to such requests? It is commonly understood in law across Canada that patients who are able to understand the consequences of their decision are able to refuse treatment or have treatment withdrawn. For example, a person dying of Lou Gehrig’s disease, who is gradually suffocating due to weakening lungs, is not forced by law to go on a ventilator, and a

person with a spinal cord injury who requires a ventilator to live is not legally required to stay on one. In this way, Canadians are given the freedom for natural death to occur. Such decisions should not be confused with assisted suicide because they do not intervene to hasten death.

By virtue of the physical state of a quadriplegic, for example, they will require the help of another person to withdraw a ventilator or stop other treatments. While this situation is morally and ethically complex, the withdrawal of life support with the individual’s permission is legal.¹⁵

In the end, no one can glamorize or simplify the process of recovering quality of life after an SCI. Similarly, no one can deny that the vast majority of individuals with SCI do return to a high quality of life in many respects, if they are given the time, therapy and support to do so.

Research shows that the vast majority of persons who undergo a spinal cord injury regain a sense of being glad to be alive, though such healing is far from immediate and will require mental, physical, psychological and spiritual adaption to an almost entirely “new normal.” Reality shattered can and is reconstructed to give different understandings of what quality of life really means.

Such recovery takes time. Spinal cord injuries bring such a sudden, complete change to the life of the individual that no one can ask someone so injured to make a final decision about their future without time to adjust. Initial wishes for death should not carry the day, because a high quality of life is recoverable.

WHAT ROLE DOES THE CAREGIVER HAVE?

If, as Dr. Chochinov states, “at least in part, it would appear, dignity resides in the eye of the beholder”¹⁶, then incumbent in any discussion of quality of life for people with a spinal cord injury is the question of the attitude of caregivers. A 2004 report by the Government of Canada further clarifies the role of society in the life of those with disabilities:

Much evidence suggests that public attitudes may themselves be critical to either advancing or hindering the inclusion of people with disabilities in our society. What people believe about individuals with disabilities underlies the treatment of those individuals in all aspects of their lives. The cost of negative beliefs or inaccurate information is high, both for people with disabilities and for society as a whole.¹⁷

No one can diminish the pain which parents and spouses experience at the injury of their loved one.

The major issues of disability are not merely problems of individual capacity or health condition, but rather questions of community commitments or neglects, in short, matters of power relations at many levels and segments of communities.¹⁸

It is beyond the scope of this paper to make comprehensive recommendations for the societal treatment of persons with a spinal cord injury. Let it simply be said that, lost opportunity on the basis of the injury in family, social engagement, and employment, for example, can be devastating to the quality of life for that individual. The offer or suggestion of death early on in the process of recovery robs the individual of the chance to regain a quality of life which brings with it a joy at being alive.

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CONCLUSION

Research shows that people with a spinal cord injury count themselves much more happy to be alive than those without such an injury would.

Research also shows that the vast majority of individuals with a traumatic spinal cord injury initially entertain a wish to die. Over a length of time largely unique to the individual, this wish declines or disappears. The injured need the ability to adjust to what is essentially a new way of life.

Because the vast majority of individuals with a spinal cord injury feel an initial desire for death, offering them the option of assisted suicide while this desire remains is effectively to encourage suicide in a moment of depression and shock. Persons thus encouraged, who commit assisted suicide because of that initial desire would die too soon to regain a sense of being happy to be alive, too soon to engage in life with family and friends in the context of their “new normal”. They would also die too soon to take advantage of possible medical treatments which the future may hold.¹⁹

Persons with a traumatic spinal cord injury do not need the offer of death at the beginning of their post-injury life; they need the prospect and reality of a renewed joy at being alive.

RECOMMENDATIONS:

- Education at the youngest levels possible develops a well-rounded appreciation for the abilities and contributions of those paralyzed by a spinal cord injury and those otherwise physically challenged
- Education can help children and adults to accept and understand that persons with an SCI can and do regain a high quality of life post-injury
- Government should continue to support local and provincial rehabilitation centres to treat those with a spinal cord injury in the weeks, months and years following the injury
- Government and private business alike must continue to produce and provide goods and services which allow people with a spinal cord injury to engage as a full member of society
- Families and spouses who are able to journey together through the changes brought on by a spinal cord injury can be foundational to the quality of life of their loved ones just by virtue of the dignity and respect given during that journey
- Assisted suicide for people with a spinal cord injury should never be made legal. This would debatably cause many individuals with an SCI to die prematurely, before they had the chance to regain a “new normal”, including a high quality of life

Endnotes

- 1 Post, M.W.M., de Witte L.R., van Asbeck F.W.A., van Dijk A.J., Schrijvers, A.J.R.. (1998). Predictors of health status and life satisfaction in spinal cord injury. *Archive of Physical Medication and Rehabilitation*. 79, pp. 395-401.
Post, M. W. M., Van Dijk, A. J., Van Asbeck, F. W. A., Schrijvers, A. J. P. (1998). Life satisfaction of persons with spinal cord injury compared to a population group. *Scandinavian Journal of Rehabilitation Medication*. 30, pp. 23–30.
- 2 Post, M.W.M, Van Dijk, A.J. et al. (1998). Life satisfaction of persons with spinal cord injury compared to a population group.
- 3 Chochinov, H.M. (2004, April 1). Dignity and the eye of the beholder. *Journal of Clinical Oncology*. 22(7), pp. 1336-1340.
- 4 Chappell, P., Wirz, S. (2003). Quality of life following spinal cord injury for 20-40 year-old males living in Sri Lanka. *Asia Pacific Disability Rehabilitation Journal*, 14:2.
- 5 Gerhart, K. A., Koziol-McLain, J., Lowenstein, S. R., Whiteneck, G.G. (1994, April). Quality of life following spinal cord injury: knowledge and attitudes of emergency care providers. *Annals of Emergency Medicine*, 23(4), pp. 807-812.
- 6 Dijkers, M. P. J. M. (2005, May/June). Quality of life of individuals with spinal cord injury: A review of conceptualization, measurement, and research findings. *Journal of Rehabilitation Research and Development*. 42(3), p. 93.
- 7 Post, M.W.M, de Witte, L.R. et al. (1998). Predictors of health status and life satisfaction in spinal cord injury.
- 8 Chochinov, H.M.
- 9 Post, M.W.M, Van Dijk, A.J. et al. (1998). Life satisfaction of persons with spinal cord injury compared to a population group.
- 10 Franceschini, M., Di Clemente, B., Rampello, A., Nora, M., Spizzichino, L. (2003). Longitudinal outcome 6 years after spinal cord injury. *Spinal Cord*, 41, pp. 280–285.
- 11 Dijkers, M. P. J. M. (2005, May/June). p. 97
- 12 McColl M.A., Arnold R., Charlifue S., Glass C., Savic G., Frankel H. (2003, August). Aging, spinal cord injury, and quality of life: structural relationships. *Archive of Physical Medical Rehabilitation*. 84, pp. 1137-44.
- 11 Krause, J.S. and Broderick, L. (2005). A 25-year longitudinal study of the natural course of aging after spinal cord injury. *Spinal Cord*. 43, pp. 349–356.
- 14 Young, J.M. and Browne, A. (2008). Choosing death in rehabilitation. *Topics in Spinal Cord Injury Rehabilitation*. 13(3), pp.18–29.
- 15 Tiedemann, M., Valiquet, D. (2008, July 17). Euthanasia and Assisted Suicide in Canada. Library of Parliament (Canada), Law and Government Division. Section B, Number 4. Retrieved December 29, 2009 from <http://www2.parl.gc.ca/Content/LOP/ResearchPublications/919-e.htm>
- 16 Chochinov, H.M. (2004).
- 17 Social Development Canada. (2004). Supporting persons with disabilities: Advancing the inclusion of persons with disabilities. A Government of Canada Report, p. 12. Retrieved October 29, 2009 from <http://www.marchofdimes.ca/NR/rdonlyres/C8B5B6A1-4E40-440E-AD00-DFC512C43B8E/0/aipd04.pdf>
- 18 Prince, M.J. (2009). *Absent citizens: Disability politics and policy in Canada*. Toronto: University of Toronto Press. p. 3
- 19 Nowoselski, S. (2009, December 15). A lifelong dream bears fascinating fruit. *The Ottawa Citizen*. p. C3.

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